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ABSTRACT

This annotated bibliography on the use of facilitated communication with people unable to express themselves was developed as part of a statewide training and technical assistance project in Maine. The 75 citations are listed alphabetically by author and date from 1986 through 1993. The items listed report on the use of facilitated communication with people having autism, severe mental retardation, and other severe disabilities. The citations address the issues of validity, accusations of child abuse under facilitated communication, and research problems. (DB)

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CREATING INCLUSIVE COMMUNITIES

A Monograph Series

Number 1

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FACILITATED COMMUNICATION

AN ANNOTATED BIBLIOGRAPHY

Prepared by

Janet Koppenhofer, Debbie Gilmer and Mary McElroy

July, 1993

Center for Community Inclusion
Maine's University Affiliated Program
University of Maine

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Previous Publications:

Creating Inclusive Educational Communities: A Monograph Series

Number 1--*Creating Inclusive Schools: A Resource Guide (1991)*

Number 2--*Creating Positive Educational Programs for Students Presenting Challenging Behavior: An Annotated Bibliography (1991)*

Number 3--*Kids Talk About Inclusive Classrooms (1992)*

This annotated bibliography was developed with funding awarded to the Center for Community Inclusion, Maine's University Affiliated Program at the University of Maine by the Bureau of Mental Retardation, Maine Department of Mental Health & Mental Retardation and the Division of Special Education, Maine Department of Education. The Center for Community Inclusion receives funding from the Administration on Developmental Disabilities, U.S. Department of Health and Human Services. The opinions expressed herein are those of the authors and do not necessarily represent those of the Maine Department of Mental Health & Mental Retardation, the Maine Department of Education, the University of Maine or the U.S. Department of Health and Human Services. For information regarding the Center for Community Inclusion please contact:

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ACKNOWLEDGMENTS

A number of individuals need to be recognized for their support of our efforts to learn and teach others about Facilitated Communication. It is through their commitment to people with disabilities that we have all been empowered.

Nicholas Koppenhofer has provided us with a wealth of information regarding facilitated communication and disability. In sharing his experiences with us we have grown immensely. We all have a great deal to learn from his wisdom and tenacity.

Roger Deshaies, Acting Commissioner of the Maine Department of Mental Health and Mental Retardation and David Noble Stockford, Director of the Division of Special Services, Maine Department of Education, have long demonstrated their commitment to individuals with disabilities through their leadership and respect for the rights of individuals with disabilities and their families. Their commitment to providing people with disabilities and their families choice, opportunity and dignity is unwavering.

It would certainly be shortsighted of us to neglect to mention the efforts of Rosemary Crossley and Doug Biklen. It is through their leadership that individuals throughout our state, the country and the world are now able to articulate their dreams. Despite significant controversy they remain steadfast in their resolve to teach others how to assist individuals without adequate communication to be heard.

And, finally, we extend our appreciation to Kelly McClymer for her contributions to the design and production of this bibliography.

INTRODUCTION

In one way or another, all communication promotes the self, defines the self, makes the self known to others. Aside from its relevance as a means of doing school work and getting educated, or of expressing feelings, facilitated communication has enabled students to convey their needs, wants, and aspirations. (Biklen, 1993, p. 156)

Facilitated Communication is a method of facilitating expression by people who have limited or no meaningful ability to express themselves. The method involves initial hand and/or arm support, pulling the hand back after each selection, slowing down the movements, assistance in isolating the index finger, verbal reassurance and emotional support and encouragement. Over time, the physical support can be faded back completely or to just a hand on the shoulder. Since Maine's initial introductory training was conducted by Doug Biklen in December, 1991 hundreds of individuals with disabilities have been given the opportunity to be heard. Throughout Maine, in schools, homes and communities, individuals with disabilities now have the opportunity to participate actively in decisions that affect their lives, to articulate for the first time their thoughts and desires, and to demonstrate their abilities.

The Center for Community Inclusion, Maine's University Affiliated Program at the University of Maine, through funding provided by the Maine Department of Mental Health and Mental Retardation and the Maine Department of Education, has been providing statewide training and technical assistance related to Facilitated Communication since September, 1992. **Facilitated Communication in Maine**, our statewide training and technical assistance project, has prepared this annotated bibliography as a resource for parents, educators, speech/language professionals and support providers.

Baker, B., Leary, M., Repa, S., & Whissel, P. (1993). Getting in touch: A workbook on becoming a facilitator. "Movin' On" beyond facilitated communication. Madison, WI: Press.

This monograph describes the methods and process used to teach staff and family members from an agency in Ontario about facilitated communication.

Barron, J., & Barron, S. (1992). There's a boy in here. New York: Simon & Schuster.

This is a story written by the alternating pens of mother and son. Sean, diagnosed as having autism as a toddler, and his mother relate their perspectives of his life growing up. It presents powerful insight regarding the often challenging and bizarre behavior associated with autism and implications for our interventions.

Biklen, D. (1990). Communication unbound: Autism and praxis. Harvard Educational Review, 60, 291-314.

This article introduced facilitated communication to the United States. Biklen richly describes what he saw at the DEAL Communication Center in Melbourne, Australia. The technique, developed there by Rosemary Crossley, was observed to be used by twenty-one individuals with autism. All typed with a hand on the shoulder although not as fluently with all facilitators. Biklen presents a review of the literature concerning autism and communication and notes how facilitated communication fits in that context. Discussed also are the typical behaviors of autism still present despite the communication and the challenge facilitation presents to our current notions of autism.

Biklen, D. (1992). Autism orthodoxy versus free speech: A reply to Cummins and Prior. Harvard Educational Review, 62, 242-256.

This is a pivotal piece in the on-going discussion about the change facilitated communication makes to fundamental ideas about severe disabilities and the very concept of mental retardation. Written in response to the Cummins and Prior (1992) article *Autism and Assisted Communication*, Dr. Biklen systematically examines the basis for their skepticism and defends the very right to communicate. Biklen concludes with the powerful statement, "maintaining certain theories about autism is no justification for denying free speech."

2 Facilitated Communication Bibliography

Biklen, D. (1992). Facilitated communication: Biklen responds. American Journal of Speech and Language Pathology, 1(2), 21-22.

This is Biklen's rebuttal to Calculator's (1992) article *Perhaps the Emperor Has Clothes After All: A response to Biklen*. He asserts that what is termed "spiritual" is nothing more than "the supportive relationship of teacher and student," something that has been studied in education literature for years. Biklen also recounts the detailed description of the method he has published in regard to Calculator's claim of ambiguity. At issue in this exchange between Calculator and Biklen is research method. Biklen states "our analyses of the field research data have been conducted within the tradition of qualitative research and grounded theory" and that empirical evidence is not lacking. He agrees that further research should be conducted.

Biklen, D. (1992). Typing to talk: Facilitated communication. American Journal of Speech and Language Pathology, 1(2), 15-17.

Dr. Biklen describes the central components of facilitated communication and its success with the first twenty-two students who were systematically followed; all twenty-two demonstrated literacy skills with nineteen producing sentences. He also recounts how students with echoed language produced typing free of stereotypic language when facilitated. This article is one in the exchange of views between Biklen and Stephen Calculator in this issue of AJSLP.

Biklen, D. (1993). Communication unbound: How facilitated communication is challenging traditional views of autism and ability/disability. New York: Teacher's College Press.

This book relates Dr. Biklen's discovery of facilitated communication while visiting Australia, his experiences in bringing this newfound information to a skeptical professional community in the United States, and the growth of interest and debate in this country. Written in the first person, this is truly a tale of an enlightening and powerful journey. In addition to sharing his and others' experiences, technique and explanation, Biklen presents sections on the change process (including the validation controversy) and rethinking disability.

Biklen, D. (1993). Notes on validation studies of facilitated communication. Facilitated Communication Digest, 1(2), 4-6.

After a brief description of the method, Biklen reviews six considerations for validation testing. 1. "When people have passed validation tests they have been working with a familiar facilitator." 2. Low confidence has been cited as a difficulty for some to facilitate. 3. Word finding problems are common and naming "a single picture with one word" as the test should be ruled out. 4. People using facilitated communication rarely have experience with any testing situation. Practicing test taking would be a remedy. 5. Quality of facilitation involves addressing specific physical problems and selections. 6. Other considerations, i.e. contexts in which people are the most successful, intrusion of echoed communication, access to typing device. The author also analyzes the O. D. Heck study (Wheeler, et. al., 1992) and finds a number of concerns, including the lack of facilitator training, a validation approach which involved confrontational testing, and the fact that word retrieval problems were not accounted for. The article identifies unobtrusive measures advocated by the author to validate the typists' words as their own.

Biklen, D. (May 1993). Controversy over facilitated communication. TASH Newsletter, 19(5), 6.

This is an introduction to a statement developed by the Facilitated Communication Institute at Syracuse University "to help parents, professionals, and legal authorities understand allegations of abuse that are made by people using the facilitated communication method." The author notes that sorting out allegations of abuse are very difficult and complex even in cases involving people without disabilities who can speak. Although any allegation must be taken seriously, the possibility of echoed language, word finding problems and the fact that people communicating are being responded to for the first time, requires extra sensitivity.

Biklen, D., & Crossley, R. (1992). Foreword. Topics in Language Disorders, 12(4), vi.

The authors describe the goals for the series of articles on facilitated communication in this issue of *Topics in Language Disorders* as defining the technique and critically examining the method.

4 Facilitated Communication Bibliography

Biklen, D., Morton, M., Gold, D., Berrigan, C., & Swaminathan, S. (1992). Facilitated communication: Implications for individuals with autism. Topics in Language Disorders, 12(4), 1-28.

This article begins with a background on autism and communication disorders. Assumptions that communication deficiencies derive from "cognitive limitations," and studies that suggest physical behaviors have communicative intent are examined. The method is described, as are the previous similar methods used and described in the literature for the past twenty years. The qualitative examination of 43 individuals (age 2 to 26) using facilitated communication is detailed and the qualitative research method is explained. Three conditions were revealed in this research that assist a speaker to begin to communicate: the communication content (structure to conversation); physical support (fading, pulling back, etc.); and, attitudinal support (assumption of competency, trust and constant opportunities to facilitate). Methods used to get beyond echolalic speech and typing are described. Six factors are listed "that seem to validate individuals' communication" such as content not known to the facilitator. A positive impact on behavior is noted although it is emphasized that facilitated communication is not a cure. Finally, the hypothesis that "people with autism experience global apraxia, affecting all aspects of voluntary physical activity" is discussed as it is supported by the authors' research findings. The fact that apraxia does not necessarily indicate cognitive deficiency and the similarities described by Sacks in his work with parkinsonism are noted.

Biklen, D., Morton, M. W., Saha, S. N., Duncan, J., Gold, D., Hardardottir, M., Karna, E., O'Connor, S., & Rao, S. (1991). "I am not autistic on the typewriter" ("I'm not autistic on the typewriter"). Disability, Handicap & Society, 6(3), 161-180.

A comprehensive introduction to facilitated communication, this article describes the method and the hand use problems it appears to remedy. The earlier reports of Crossley and Biklen are described. Examples of verbal and typed echoed language are shared and techniques to help alleviate the facilitated echoes are included. The continuation of typical behaviors despite intelligent typing output is examined as is how individuals felt about that behavior. A section on qualitative validation is included. The aid users' own words on why they still needed even just a light touch from a facilitator to type are interesting; the facilitator gave confidence that she was "not going to mess up."

Biklen, D., & Schubert, A. (1991). New words: The communication of students with autism. Remedial and Special Education, 12(6), 46-57.

This article provides a description of the first year using facilitated communication for twenty-one students in the Syracuse area public schools. The "getting started" process is described, as are the issues of unexpected literacy and implications for schooling. This article provides an excellent introduction to facilitated communication.

Bligh, S., & Kupperman, P. (1993). Court accepts protocol for testing the validity of facilitated communication. Unpublished manuscript.

This report describes a protocol developed and used by the Juvenile Court in Marion County, Indiana. The case involved a 10-year-old girl diagnosed with legal blindness and mental retardation who, through the use of facilitated communication, reported instances of sexual abuse. In an effort to determine the validity of the accusations, the protocol was used to determine who was originating facilitated communication messages.

Borthwick, J. S., Morton, M., Biklen, D., & Crossley, R. (May, 1993). Severe communication impairment, facilitated communication. TASH Newsletter, 19(5), 6-7.

This article outlines a systematic approach for use when abuse is alleged by a person using facilitated communication. Five key questions are presented. 1. "Can the person communicate through facilitation?" Incidental message passing or having two facilitators receive the same message are cited as ways to accomplish this. It is noted that people with word finding problems may be only able to "pass" a message in general terms. 2. "Has an allegation actually been made?" The message may be incomplete (the facilitator simply stopped too soon), telegraphic (the addition of a verb changes the content dramatically) or simply ambiguous and in need of clarification. Word finding problems may also cause a person to be unable to think of exactly the correct word they intend; clarifying questions may be necessary but they must not be leading questions. If at all possible confirm the message with a second facilitator. 3. "Is the allegation credible?" The authors point out that validation of the communication is not validation of the allegation, and that the same standards must apply as they would to a charge made orally. 4. "Does the allegation appear to be true?" As in any case evidence should be collected and supported if possible by independent witnesses or information. 5. "How should the case be handled?" The facilitation may well deteriorate under the pressure of a formal court hearing. The authors state that if done correctly facilitated communication provides a "powerful tool for people who until now have been denied the protections others take for granted."

6 Facilitated Communication Bibliography

Butler, K. (1992). From the editor. Topics in Language Disorders, 12(4), iv-v.

In this commentary by Dr. Butler issues and debate around facilitated communication are outlined. She cautions readers not to be "hurried away by excitement alone" (quoting Epictetus), and urges further study.

Calculator, S. N. (1992). Facilitated communication: Calculator responds. American Journal of Speech and Language Pathology, 1(2), 23-24.

Calculator points out a lack of descriptive information on the students with severe disabilities that Biklen (1990) cites who are facilitating fluently and asks "How did they get to the point at which they are now communicating?" He theorizes that prior therapy or educational experience might explain the students' linguistic skills. Calculator also cites sources that are contrary to Biklen's apraxia hypothesis.

Calculator, S. N. (1992). Perhaps the emperor has clothes after all: A response to Biklen. American Journal of Speech and Language Pathology, 1(2), 18-20.

Although the author makes it clear at the onset that he believes that communication does actually happen in individual cases he notes, "this communication technique remains one that is characterized by its ambiguity, mystique, recurring anecdotes and spiritual underpinnings." Calculator points to a lack of theoretical basis and a lack of explanation as to why it works and calls the praxis argument "insufficient." He calls for further research to identify what factors are instrumental for facilitated communication to work and how people's lives change (or don't change) after facilitating.

Calculator, S. N., & Singer, K. M. (1992). Letter to the editor: Preliminary validation of facilitated communication. Topics in Language Disorder, 12(5), ix-xvi.

This article describes the authors' quantitative research with five boys, age 6 to 16, diagnosed as having severe to profound mental retardation and who had been facilitating for a minimum of three months. Facilitators wore headphones which produced masking white noise while the Peabody Picture Vocabulary Test was administered with and without facilitation. Three students showed marked improvement when facilitated. (One student's age equivalent changed from 2.2 years to 15.4). One student whose score did not change was retested one week later under the same conditions but with one of the authors administering the test instead of the school speech language pathologist. His score then rose from 2.0 to 6.1. The other student whose score did not improve was later noted to have had a recent change in medication and was "limp" and "tired." When later asked by his facilitators why he didn't perform better on the test he typed, "stupid, stu, stu." In conclusion the authors state that it is "irresponsible to claim newly discovered abilities before such skills are empirically validated."

Chazin, S. (1993, March). The Secret Life of Arthur Wold. Readers Digest, pp. 96-101.

This is the story, told from the perspective of the parents, of a young man who was considered to have severe mental retardation for the first 24 years of his life. It relates his ability to communicate and his full comprehension of the world around him.

Collins, A. J. (ed.) (1992). Facilitated communication: A reference book. Annandale, VA: National Association of Private Residential Resources.

This monograph is a compilation of information and materials on facilitated communication used to provide an introduction and overview of the technique. It includes handouts from Biklen's workshops, "getting started" materials and a copy of one of Crossley's papers.

8 Facilitated Communication Bibliography

Crossley, R. (1990). Communication training involving facilitated communication. Paper presented to the annual conference of the Australian Association of Special Education, Canberra Australia.

Crossley begins by defining the difficulties faced by individuals with both a severe communication impairment and fine motor skills inadequate to write or use manual signs. Described as being "caught in a downward spiral" she relates her belief that individuals are placed "where their speech and motor impairments are seen as being the unavoidable corollary of the intellectual impairments." A case study is presented, as are the "common problems requiring facilitation." The technique is succinctly described including the distinction of facilitated communication from co-active movement. The author warns against excluding individuals from facilitated communication training on the basis of prior negative testing.

Crossley, R. (1992). Getting the words out: Case studies in facilitated communication training. Topics in Language Disorders, 12(4), 46-59.

A companion piece to Crossley & Remington-Gurney (1992) *Getting the words out: Facilitated communication training*, three case studies of facilitated communication are examined by Rosemary Crossley which illustrate the diversity of disabilities and communication deficits that the method can benefit. Anne McDonald has athetoid cerebral palsy and severe physical impairments. She is also the first known user of facilitation in Australia and Crossley relates the arduous details of Anne's road to full communication. Barbara was a 25 year old with phenylketonuria with fewer than twenty manual signs when she was brought to DEAL. She improved her communication rapidly with facilitation, and this case study illustrates the emphasis placed on quickly moving to independent typing at DEAL. Also included is Barbara's experience in a court of law after alleging that a male employee at her residence assaulted her. Finally, twelve year old Paul's experience with facilitation is described. Paul has Down syndrome and variable language difficulties; on some days he could speak complex sentences and at other times could not manage one word replies. Perseveration was frequently a problem. In less than a year, Paul was mastering the regular curriculum in school using facilitation. Crossley comments that sixty years ago it was the conventional wisdom that the "physical impairment in cerebral palsy mirrored the severity of the intellectual impairment..." and unexpected achievements of individuals with Down syndrome could parallel such underestimation.

Crossley, R. (1993). Preliminary validation of facilitated communication: A correction [Letter to the editor]. Topics in Language Disorders, 13(4), xv-xvi.

This is a response to Calculator and Singer (1992) *Letter to the Editor, Preliminary Validation of Facilitated Communication*. The author points out an error in the representation of the results of the Intellectual Disability Review Panel concerning the validity of assisted [facilitated] communication. She states that the Panel found validity in the use of assisted [facilitated] communication in four of the six clients participating in the studies.

Crossley, R., & McDonald, A. (1980). Annie's coming out. Middlesex, England: Penguin Books Ltd.

Rosemary Crossley and Annie McDonald relate their story of discovery and eventual freedom for Annie from a distressing and oppressive life in an institution. Annie, a teenager who had spent the large majority of her life in the institution, begins to communicate with Rosemary who was a teacher employed by the institution. The controversies, struggles (including court battles to determine competency) and excitement in Annie's "coming out" are shared by Rosemary and Annie. This story relates the discovery of what is now termed facilitated communication. It is a "must read" for family members and support providers interested in facilitated communication or individuals with disabilities: one's perception of disability will be changed forever.

Crossley, R., & Remington-Gurney, J. (1992). Getting the words out: Facilitated communication training. Topics in Language Disorders, 12(4), 29-45.

This is a succinct article that covers the key elements of facilitated communication. Why other augmentative communication systems may not work for persons with severe hand impairment is explained in order to lay the groundwork for showing why facilitation works. Included is a detailed account of the work at the DEAL Communication Centre; the clients who are served there, their disabilities and their success in communicating are described and documented. The different hand use problems are discussed, as are issues around literacy, including word finding problems. Fading support and validation of communication are covered briefly. The article concludes with "Future Directions." The authors argue that if the fine motor skills of preschoolers with any delay in speech are screened and remediated they will be able to access communication devices independently and facilitated communication will become unnecessary. To do so, state the authors, "it will be necessary to change focus from diagnosis and labeling to functional assessment and remediation."

10 Facilitated Communication Bibliography

Cummins, R. A., & Prior, M. P. (1992). Autism and assisted communication: A response to Biklen. Harvard Educational Review, 62(2), 228-240.

This article was written in response to Biklen's (1990) *Communication Unbound: Autism and Praxis*. It addresses the questions: How did people with severe disabilities learn to read?; Why can't they type with anyone?; and Why does the communication 'break down' in validation studies. Biklen's rebuttal *Autism Orthodoxy Versus Free Speech* (1992) is presented as a follow-up to this article in the same issue.

Datlow Smith, M., & Belcher, R. G. (1993). Facilitated communication with adults with autism. Journal of Autism and Developmental Disorders, 23(1), 175.

This article describes a validation study conducted with eight men with autism who were trained in the use of facilitated communication. Results indicated that the men typically produced typed material that was at a level similar to their verbal abilities.

Dillon, K. (1993). Facilitated communication, autism, and Ouija. Skeptical Inquirer, 17, 281-287.

In this article the author uses parallels between facilitated communication and Ouija to identify and discuss concerns about the validity of facilitated communication.

Donnellan, A. M., Sabins, L. A., & Majure, L. A. (1992). Facilitated communication: Beyond the quandary to the questions. *Topics in Language Disorders*, 12(4), 69-82.

An article that raises interesting and helpful points of departure for further consideration that those "who dismiss facilitation out of hand...must explain why learners with autism would consent to giving other people's messages day after day for years." Facilitated communication, the authors assert, is not a "party trick," thus individuals may simply not want to share their thoughts to meet others' demands for proof. Investigating facilitated communication may require techniques other than the usual research designs and the case history methods of Luria (1986) and Sacks (1990) are cited as an example. The article states that "the danger of not offering the option of facilitation...is far greater than the danger of raising false hopes for families...Indeed families have survived disappointments far greater ...than they will if (it) turns out to be a relatively ungeneralizable phenomenon." The authors call for a "clear technology of facilitated communication" to avoid a proliferation of inadequate and ineffective techniques.

Duval, Dina. (1992, July 12). John joins a world that hardly knew him. *Lewiston Sun-Journal*.

This is an account from Lewiston, Maine of a young boy, John, and his parent, Kathy Williamson. It describes what it is like to live with autism and how facilitated communication has changed their lives. School personnel describe how John's personality and his school program have changed. John is quoted, "Give me a chance to prove myself. Then they will believe me."

Eastham, M. (1992). Silent words. Ottawa: Oliver & Pate.

This is the story of David Eastham's life living with autism, his and his family's struggle to assure him the right to communicate, and an early discovery of what is now termed facilitated communication. Thanks to his mother's persistent teaching, at the age of 16, in the late 1970's, David began communicating using wordboards and keyboards with support provided that was faded back to a hand on his shoulder. "This is a powerful story, faithfully told, relating a struggle for acceptance as a thinking, feeling human being." David's *Forever Friends* poetry compilation is reprinted here along with teaching guidelines, methods and materials that his mother designed and used.

12 Facilitated Communication Bibliography

Experts weigh communication method. (1993, April). Maine Sunday Telegram, p. 10B.

Stephen Calculator's validation studies of facilitated communication are discussed and a parent's success story is told. The article emphasizes the controversy and states "...there should be testing to prove once and for all whether facilitated communication...really works."

Goad, M. (1992, July 12). Computer helps break silent wall surrounding autistic Lewiston boy. Maine Sunday Telegram, pp 1A, 14A.

This newspaper account of a young boy in Maine with autism, John Williamson, tells of life before and after he began to use facilitated communication. The method is briefly described and explains how John can show how bright he is. It also brings to light what a health risk it is not to be able to communicate: John had a secondary health problem undiagnosed until he could fully express himself.

Goldberg, T. E. (1987). On hermetic reading abilities. Journal of Autism and Developmental Disorders, 17(1), 29-44.

This article reviews the literature on the "savant syndrome" of hyperlexia and autism. The author uses "hermetic reading" interchangeably with the term hyperlexia. The studies reviewed reported that these children with severe expressive and motor disabilities had reading abilities "at a level well above chronological or mental age." In one study (Mehegan & Dreyfus, 1972) of 12 young children "all instantly commenced reading if material was available." This article, although not specifically about facilitated communication, provides insights into the unexpected literacy skills demonstrated through the technique.

Grandin, T., & Scaviano, M. (1986). Emergence: Labelled autistic. Novato, CA: Arena Press.

This autobiographical narrative was written by a woman who is referred to in the text as a "recovered autistic individual." An informative story, the author enlightens the reader about her feelings, fears and communication struggles. Particularly interesting are her insights into the tactile difficulties experienced by people with autism. Now a world renowned expert in the design and construction of cattle facilities, Grandin received her Ph.D. from the University of Illinois at Urbana in 1988.

Green, G. (1992, October 28). Facilitated communication: Scientific and ethical issues. Paper presented at the E. K. Shriver Center for Mental Retardation UAP Research Colloquium, Boston MA.

This manuscript provides a review of current controversies in the use of facilitated communication. The author describes research concerning the descriptive, qualitative studies used to support the success of facilitated communication. Empirical studies are also presented and discussed. The article concludes with a section on ethical issues relating to facilitated communication.

Green, G. (1993). What does research tell us about facilitated communication? Manuscript submitted for publication.

After reviewing qualitative studies and numerous anecdotal reports of the validity of facilitated communication, the author states that basic scientific methods for evaluating effectiveness are absent. In several empirical studies using standard scientific methods designed to reveal the source of communication or the presence of unexpected literacy skills, none of the results indicated validity of facilitated communication. The author reports one empirical evaluation of facilitated communication (Calculator & Singer, 1992) that appeared to differ with the above results and notes that this study may have been flawed.

Hill, D. A., & Leary, M. R. (1993). Movement disturbance: A clue to hidden competencies in persons diagnosed with autism and other developmental disabilities. "Movin' on" beyond facilitated communication. Madison, WI: DRI Press.

This monograph describes a possible theory for why facilitated communication works with individuals with autism.

Hudson, A., Melita, B., & Arnold, N. (in press). Assessing the validity of facilitated communication: A case study. Journal of Autism and Developmental Disorders.

This case study relates the assessment of the validity of facilitated communication used by a 29 year old woman diagnosed as having mental retardation using a procedure outlined by the Australian Intellectual Disability Review Panel.

14 Facilitated Communication Bibliography

Jacobson, J., Eberlin, M., Mulick, J., Schwartz, A., Szempruch, J., & Wheeler, D. (1993). Autism, facilitated communication and future directions. In J. L. Matson (ed.), Autism, etiology, assessment, and intervention (pp. 93-132). Sycamore, IL: Sycamore Press.

In this chapter, the authors "review the current context of services for people with developmental disabilities, summarize new perspectives on language development, and critique the most recent and fashionable zeitgeist." Most of the discussion focuses on facilitated communication (recent research, rationale for facilitated communication, the need for authenticity). Included is a piece reviewing the literature on language and autism. The authors express concern over the use of "unproductive and socially harmful therapeutic endeavors" and call for the use of clinical, objective standards to confirm the value of any treatment for general use.

Jowonio School. (1992). First words: Facilitated communication and the inclusion of young children. Syracuse, NY: Author.

Jowonio School is an inclusive preschool in Syracuse with a long tradition of including students with autism. This comprehensive manual provides information and strategies for getting started with facilitated communication with very young children and includes practices that support all students in the preschool classroom.

Koppenhaver, D. A., Coleman, P. P., Kalman, S. L., & Yoder, D. E. (1991). The implications of emergent literacy research for children with developmental disabilities. American Journal of Speech Language Pathology, September 1991 38-44.

Although not about facilitated communication specifically, this research provides some answers to the puzzle of how individuals with no academic schooling or even everyday opportunities to develop literacy have somehow done so as revealed in their communication through facilitation. This article notes four conclusions about emergent literacy in children without disabilities: (1) the process of learning to read and write is a continuum that begins at birth, and perhaps before; (2) reading, writing, speaking, and listening abilities develop concurrently and interrelatedly, rather than sequentially; (3) the functions of literacy are as integral to literacy learning as the forms; and (4) children learn written language through active engagement with their world. The article concludes that the literacy needs of children with developmental disabilities can be systematically addressed.

Krum, J. M. (1992). Facilitated communication: The promises and the problems. The New Hampshire Challenge: Disability Issues From a Family Perspective, 5(2), 1-7.

This article begins by pointing out how facilitated communication has shaken the most basic assumptions about disabilities held by parents and professionals. In large part an interview with Rosemary Crossley, it describes how individuals have had their typing devices taken from them after an evaluation alleged to prove that communication was not initiated by them. Crossley comments "What people are doing to individuals has very little to do with science and nothing at all to do with human happiness." She also urges to "give services...by need" rather than label. The research issue is discussed with comments by Biklen and Calculator.

Kurtz, A. (1992). On testing for validity. New England Newsletter on Facilitated Communication, 1(1), 5-7.

The author describes the inherent difficulties in third-party validation of facilitated communication: "the distinction between pulling a person back to prevent mistakes and guiding someone to the letters might not be clearly observable;" misspellings can be difficult to interpret; and physical correction, modeling, or verbal prompting and encouragement cannot occur freely in a testing environment. The relationship of skepticism to reduced enthusiasm and the time that testing takes away from free expression are discussed.

Lehr, S. (1992). If you look in their eyes...you know: Parents perspectives on facilitated communication. Syracuse, NY: Institute of Facilitated Communication, Syracuse University.

This is a manual written for parents by a parent. It introduces facilitated communication, provides strategies and "how-to's," and shares the experiences of families in the Syracuse area. Written in an easy to understand style using frequently asked questions as section headings ("Is it right for my child?" "Is it too late to try?" "Will it stop the behavior problems?") Lehr imparts her belief in the capacity of individuals with disabilities and the need for emotional support for facilitated communication speakers. This is a 'must read' for parents, teachers and speech/language professionals.

16 Facilitated Communication Bibliography

MacDonald, S., & Bien, A. (1992, June 14). Now I can tell mom I love her. Woman's World, p. 51.

A brief piece that tells of Arthur Wold and his family. Arthur is an adult who is non-verbal and who began using facilitated communication at the age of twenty-nine. This article begins with the perspective of Arthur himself, imagining how painful it must have been as a child to understand completely and be unable to express anything.

Makarushka, M. (1991, October 6). The words they can't say. New York Times Magazine, pp. 33, 36, 70.

This article provides an excellent description of facilitated communication, techniques and personal experiences. Makarushka summarizes facilitated communication, its introduction by Dr. Doug Biklen to the United States from Australia, and the controversy and skepticism surrounding it. The words of Ben, Jeff and Lucy serve as powerful testimony to the impact that facilitated communication has made on their lives.

McLean, J. (1992). Facilitated communication: Some thoughts on Biklen's and Calculator's interaction. American Journal of Speech and Language Pathology, 1(2), 25-27.

This article makes the case that although objectifying the procedures and providing a theoretical basis for facilitated communication are important, it is also important to not dismiss ideas that are "unconventional in terms of past practices and past knowledge."

Moore, S., Donovan, B., Hudson, A., Dykstra, J., & Lawrence, J. (1993). Evaluation of facilitated communication: Eight case studies. Manuscript submitted for publication.

An analysis of the ability of eight people with disabilities to communicate using facilitated communication is offered in this article. Using the assessment procedure outlined by the Intellectual Disability Review Panel in Australia this report determines that none of the subjects demonstrated an ability to communicate using facilitated communication.

Mulick, J., Jacobson, J., & Kobe, F. (1993). Anguished silence and helping hands: Autism and facilitated communication. *Skeptical Inquirer*, 17, 270-280.

This article presents arguments against the validity of facilitated communication. The authors describe the characteristics of autism and caution that parents of children with autism are vulnerable to the adoption of untested techniques such as facilitated communication. The authors believe that the theory professed by Professor Douglas Biklen (1990) concerning the basis of autism as a form of developmental apraxia lacks scientific evidence. They conclude that the claims of facilitated communication proponents are extravagant and, at best, are "a false ray of hope for many families."

Oppenheim, R. C. (1974). Effective teaching methods for autistic children. Springfield, IL: Charles C. Thomas Publisher.

Oppenheim describes the teaching methods she developed and used as a teacher of students with autism. One of these methods, hand-over-hand support to assist with handwriting, has been identified as a forerunner of what is now termed facilitated communication.

Prizant, B. M., & Rydell, P. J. (1984). Analysis of functions of delayed echolalia in autistic children. *Journal of Speech and Hearing Research*, 27, 183-192.

The delayed echoic utterances of three boys diagnosed with autism were analyzed from videotape. Delayed echolalia was defined as having to meet one of two criteria: the utterances "had to be beyond the child's level of grammatical complexity when compared to creative utterances" and/or "they had to be identified as memorized routines by child's language clinician or teacher."

Regal, R., Rooney, J., & Wandas, T. (1993). Facilitated communication: An experimental evaluation. Unpublished manuscript.

This article begins with a review of the current controversy over the validity of facilitated communication. It goes on to present a study conducted with 19 adults. Using a simple information passing design, subjects were to relate information about color, shape and quantity of items pictured on a card. Results indicated a lack of validity of facilitated communication for all subjects in the study.

18 Facilitated Communication Bibliography

Richard, J., Jackson, K., Ulrich, M., & Ulrich, A. (1993). First hand: Personal accounts of breakthroughs in facilitated communicating. "Movin' on" beyond facilitated communication. Madison, WI: DRI Press.

This monograph presents the accounts of three individuals and their introduction to facilitated communication.

Rimland, B. (1992). A facilitated communication "horror story." Autism Research Review International, 6(1).

The story of an Australian family is recounted. Charges of abuse against family members were made while using facilitated communication. This article also reviews the validation studies carried out to "test" the person's ability to communicate.

Rimland, B. (1992). Facilitated communication: Now the bad news. Autism Research Review International, 6(1).

Allegations of abuse that were made through facilitated communication are related. Rimland urges that validation or "blind studies" be used to insure that charges are not made by the facilitator.

Rimland, B. (1992). Facilitated communication: Problems, puzzles and paradoxes: Six challenges for researchers. Autism Research Review International, 5(4).

Rimland recounts the enthusiasm for facilitated communication in the field of autism, but promotes the use of blind studies in a controlled testing situation. Researchers are encouraged to find ways to validate facilitated communication and to protect it from manipulation by facilitators. Rimland also suggests researching who facilitated communication works for, the role of touch, why the quality of communication varies so much and why, despite high-quality communication, people's lives generally remain unchanged.

Rimland, B. (1993). F/C under siege. Autism Research Review International, 7(1).

This article gives a brief overview of current media coverage, research findings and legal issues concerning facilitated communication. Of note are the cases mentioned where persons who have been accused (through the use of facilitated communication) of crimes, have had the allegations dropped, and are now suing responsible parties.

Rosse, R. L. (1993). A statement of position on facilitated communication. (Unpublished manuscript).

The author believes that the use of facilitated communication has not been validated and that it is dangerous to even attempt to use facilitated communication. He cites legal cases in California, New York, Australia, and Minnesota. The possible devastating effects of false accusation are explored.

Sanborn, T. (1993, May 20). Give Ben a chance. Waterville Morning Sentinel, pp. 27-28.

This is an account of Ben Rossignol, a six year old boy with autism who lives in Waterville, Maine. Unable to speak or sign, Ben has been using facilitated communication since July, 1992. Life before and after facilitated communication is movingly described by Ben and his mother Debbie Rossignol. An accompanying article (*FC sounds good, but is it real?*) addresses the skepticism that questions who is doing the typing. The role of facilitation in overcoming motor planning difficulties is discussed, as are the formal studies that allege to variously prove or disprove facilitation. Ben's mom, Debbie, is quoted as saying "Why? Why would anyone fake it?" Ben Rossignol's technical account on the paper making process that he had read about in a book of his father's is related. He was facilitated by his mother at the time, who says "there is no way I would have known that stuff." Initially skeptical, staff at Ben's school now facilitate with him regularly.

Schubert, A. (Ed.) (1992). Facilitated communication resource guide. Brookline, MA: Adriana Foundation.

This is a comprehensive resource manual that covers the role and responsibilities of the facilitator, getting started (including set work), support, equipment, validation issues, using FC across settings, and fading support. A final section on "Major Challenges" includes essays written by a number of individuals on topics of significance to facilitated communication.

20 Facilitated Communication Bibliography

Shane, H. (1993). The dark side of facilitated communication [Letter to the editor]. Topics in Language Disorders, 13(4), ix-xv.

The author responds to the August, 1992 *Topics in Language Disorders*, 12(4), which focused on facilitated communication. Outlined are a number of his concerns regarding the use of facilitated communication. These include the investment of time and money in potentially inappropriate communication systems, accusations of sexual abuse, changes in lifestyle, and educational placement.

Shapiro, J. P. (1992, July 27). See me, hear me, touch me. U.S. News and World Report, 63.

Featuring Ben Lehr, this piece briefly describes the process, history and controversy of facilitated communication. Parents, Dr. Biklen, attorneys and even a magician are quoted but Ben Lehr gets the last word.

Silliman, E. R. (1992). Three perspectives of facilitated communication: Unexpected literacy, Clever Hans, or enigma? Topics in Language Disorders, 12(4), 60-68.

The validity of facilitated communication is seen from three perspectives: the plausible, skeptical and enigmatic. The plausible perspective uses and refines the qualitative research method, and views the unexpected literacy as a challenge to orthodox view of autism. The skeptical perspective views the conclusions about the effectiveness of facilitated communication as unwarranted because they violate conventional knowledge about the disorder. Also, the global apraxia theory theorized to account for the communication difficulties is unproved, and instead the skeptical perspective theorizes that the facilitator is providing subtle nonverbal clues. The enigmatic perspective "neither rejects the findings outright nor accepts them as inherently plausible and seeks "a theoretical lens" that will make sense of the strategies that comprise the method.

Spake, A. (1992). Breaking the silence. Teacher Magazine, 3(9), 14-21.

This article describes the changes that have occurred in a classroom in Virginia for students with autism since the introduction of facilitated communication. The changes in curricular content and behavioral strategies now taking place in the classroom are dramatic. The students' parents also relate their experiences including their initial skepticism.

Stehli, A. (1991). The sound of a miracle. New York: Avon Books.

This is a true story of a mother's struggle to help her daughter overcome autism. Georgianna's diagnosis of autism did not deter her mother from seeking the best education and supports for her daughter. This included auditory training which freed Georgie of her hypersensitive hearing. "You mean the Atlantic Ocean doesn't sound like a tidal wave? I thought everyone heard it that way and coped with it better than me."

Thompson, T. (1993). A reign of error: Facilitated communication. J.F.K. Center Newsletter, Nashville, TN: JFK Center for Research on Human Development.

This article begins by comparing the facilitated communication "phenomenon" with the psychoanalytic breakthroughs promised by Bettelheim's "refrigerator mother" theory of autism: facilitation is "the latest incarnation of the 'captive-within-one's own body' metaphor." Thompson's description of facilitation does not appear accurate: "a teacher or aide repeatedly lifted the student's hand to the student's head height and then as they allowed the hand to drop, guided it toward the keys." Readers of this article are encouraged to read Biklen & Schubert (1991) for description of proper facilitated communication technique.

Wheeler, D. L., Jacobson, J. W., Paglieri, R. A., & Schwartz, A. A. (1992). An experimental assessment of facilitated communication. Mental Retardation, 5(2), 1-7.

Also referred to as the O. D. Heck study. This article presents a detailed account of a blind study that purports to prove that facilitators, albeit "unknowingly," determined what was typed in a formal testing situation. The article concludes that any important communication conveyed through facilitation (i.e. statements of self-determination) should be substantiated (if possible).

Whitehouse, D., & Harris, J. C. (1984) Hyperlexia in infantile autism. Journal of Autism and Developmental Disorders, 14(3), 281-289.

The hyperlexia (or exceptional word decoding ability) of twenty boys with autism was analyzed as was the wide variation in intelligence testing results. The authors note that hyperlexia also occurs in nonverbal children "who can point to words as they are called out...." The literature on hyperlexia is reviewed as is the "mechanism of the syndrome."

Williams, D. (1992). Nobody nowhere: The extraordinary autobiography of an autistic. New York: Doubleday.

"This is the story of two battles, a battle to keep out 'world' and a battle to join it....If you sense distance, you're not mistaken: it's real. Welcome to **my** world." Australian Donna Williams wrote the story of her life originally as a way to self discovery and to "see that my life had belonged to me." At age twenty five Williams had just discovered the word "autism" and felt she had finally found a label to hang on the painful difficult struggle that had been her life. She took her book to a psychologist to find out "once and for all why I was like this." The psychologist immediately saw that Williams did indeed have autism and felt that her book should be published to help others understand autism. She experiences hyper-acute vision and hearing often typical of autism and characterizes herself as "extremely restless" rather than hyperactive. She continues to struggle with an inability to be touched and to display emotions that she feels. As a child she had echoed language, spun and rocked. Although she managed to get through college, portions of her life were spent on the street, all the while struggling with the then unidentified autism. It was only after she discovered she was hypoglycemic and had severe food allergies was she able to begin to write. The entire book is put in terms of "my world" and "the world." Williams attempts to define autism and make suggestions for dealing with it. What she has to say about language especially, is consistent with and very interesting in regards to, facilitated communication. Williams maintains that autism is neither mental retardation or mental illness.

Wolfensberger, W. (1992, August/October). The facilitated communication craze: The cold fusion of human services. Training Institute Publication Series, pp. 39-46.

Facilitated communication is analyzed from the viewpoint of a "craze" or "culture." After identifying characteristics which have historically been aspects of crazes, and can be seen in the facilitated communication culture, the article describes potential harm which may result.

Woo, L. A. (1992). Exploring autism and communication devices. Team Rehab Report, 3(8), 23-27.

Although facilitated communication is not specifically mentioned, this is a useful guide to devices, especially ones with voice output. Considerations regarding the severity of the physical disability in choosing a device and how to get funding are also covered.

Woods, E. N. (1992). I not handicapped in my brain. Clinical Management 12(3), 28-37.

This article summarizes the history of facilitated communication, our traditional assumptions about the capacities of individuals with autism and other disabilities, and relates the Adriana Foundation's introduction and involvement with facilitated communication. It includes an insert on the implications for delivery of physical therapy to youngsters.

Woods, E. N. (1992). Michael's road to communication. Clinical Management 12(3), 38-42.

This is a delightful story of one youngster's introduction to facilitated communication with personal accounts from his mother. Michael is six years old and had previously been presumed to have significant cognitive delay. Facilitated communication and its impact on family and school life are shared.